HIT Policy and Standards Committee
Patient Generated Data Hearing

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Testimony

Panel 1: Uses of Patient Reported Information in Managing Health
- Nikolai Kirienko, Patient
- Kate Goodrich/Patrick Conway, CMS
- David Lansky, Pacific Business Group on Health
- Philip Marshall, Healthline Networks

Panel 2: Emerging Practices
- Moderator: Leslie Kelly Hall
- Judy Hibbard, University of Oregon
- Barbara Howard, CHADIS
- Elliot Fischer, Dartmouth
- Suzanne Heurtin-Roberts, National Cancer Institute
- Neil Wagle, Brigham and Women's Hospital
- John Amschler, Quantified Self
Panel 3: Policy Issues Related to Patient Reported Data
• Deven McGraw, Health Privacy Project
• Prashila Dullabh, NORC
• Chad P. Brouillard, Foster & Eldridge, LLP

Panel 4: Challenges
• Patti Brennan, Project Health Design
• Steve Downs, Robert Wood Johnson Foundation
Overview

- CMS instruments HCAHPS and other patient reported outcome measures will grow
- Patient generated health data (PGHD) White paper presented
  - “PGHD complemented provider-directed capture and flow of health-related data across the health care system.”
  - Use cases and workflow technical descriptions
    - Foundation for S&I
Overview

• PGHD are not equally helpful to every patient, provider, or situation in generating improvements in health

• Success shown where expectations set
  – Frequency of sharing
  – Data to share
  – Use by providers
  – Accuracy

• Patient reported outcomes can complement traditional clinical and administrative data
Overview

• The physician is responsible only for the use of the PHR data that the physician has actively chosen..... and specifically incorporated into the patient’s active medical care.

• Patient access to education materials important to avoid unnecessary communication
  – Literacy, language discussed

• PGHD is an important safety check
Overview

• Consider Stage 2 MU support
  – Patient messages
  – Questionnaire responses
    • Previsit
    • Experience of care
    • Quality measures

• Consider Stage 3 MU support
  – Point of care
  – Patient initiated
  – Prior to visit
  – Collaborative care plans
Overview

• Recommend a progression of measures
  – Volume of use
  – Types of use
  – Use itself

• White Board as a metaphor for collaborative care communication
  – Inpatient and beyond

• VA believes PGHD as a key component to improve care and health status
Overview

• Emphasis
• Experience and value
  – Improving health status
  – Standardization
  – Sharing and Workflow
  – Synchronization
  – Security
• Registries as an important part of PGHD collection and dissemination
• Mobile will be a game changer
Overview

• Standards and structure of PGHD important for adoption and integration into workflow
• Validated tools for patient reported outcomes needed
• Investigate new ways PGHD to interoperate
  S&I recommended
  – API
  – DIRECT
  – Consolidate CDA
Overview

- **Patient reported outcomes PROMS**
  - Multimodal delivery and collection
    - IVR
    - Patient facing system
  - Concerns upfront
    - Workflow
    - Information overload
    - Liability
  - Implementation gone better than expected
    - Patients positive
    - Workflow not adversely impacted
Overview

• Patient Activation Measures (PAM) scores
  – PAM PGHD contribute to clinician understanding of patient knowledge, skill, and confidence for managing health

• Pediatric/family/physician PGHD high area of satisfaction and collaborative care
  – Modular approach for EHR “bolt ons” and PFS
Conclusions

- PGHD
  - Accepted into EHR
  - Standardized
  - Interoperable
  - Multiple respondents
  - Include patient facing systems
  - Shared decision making
  - Include expert systems outside EHR
  - Include Quality
  - Not limited by legacy systems
Value of PGHD

Patient

Provider
Value of PGHD

Provider

Care Team

Patient
Conclusions

- Standard of care is evolving and may include PGHD in the near future
- Where implemented PGHD has improved quality and patient confidence
- PGHD for values, intolerances, AD, and preferences may fit well within CPOE
- Workflow, structured data, and expectations should be well defined and understood
- New technologies like mobile health and new data sources may overwhelm providers who have not initiated structured PGHD efforts
Conclusions

• Patients are the source of the majority of data in the record, PGHD is a logical next step

• PGHD matter because they allow clinicians to see a richer picture of the patient’s day-to-day health

• All PGHD does not need to go into EHR
  – Incl necessary to clinical decision making

• Value based reimbursement may make PGHD more pervasive

• Concerns exist, however pilots proved positive
Conclusions

• Patients are eager to participate and are more engaged in care and treatment
• Patients can provide accurate and useful information
• Processing PGHD will require computing and human intervention
• Attribution is an important part of acceptance
• Process for PGHD by providers will vary
• Data structure should standard and constant